



**Governor's Advisory Council
To The Division of Developmental Disabilities**

March 15, 2018

1056 Governor's Avenue
Dover, DE

Council Members:

Terri Hancharick, Chair
Tim Brooks
Stan Trier
Susan Pereira
Angela Sipple
Tom Rust

Staff Members:

Marie Nonnenmacher, Director
Marissa Catalon
Katie Howe
Terry Macy
Lynda Lord
Rick Kosmalski
Nicole Lawless, Minutes

Guests Present:

Terry Olson, The Arc of Delaware
Vivian Turner, CERTS, Inc.
Dr. Charmaine Wright, Center for Special Health Care Needs
Christine Sowinski, Center for Special Health Care Needs

Review of Previous Meeting Minutes

Council members reviewed and approved the minutes from the January and February meetings.

Old & New Business

Center for Special Health Care Needs

Dr. Charmaine Wright led a presentation on the Center for Special Health Care Needs based out of Wilmington Hospital. Dr. Wright began the presentation with an overview of the history of the transition care program. Alan Freedland and Mary Stevens, both of whom previously served as Directors of the Center for Special Health Care Needs, created the Christiana Transition Care Program over ten years ago. Throughout the presentation, Dr. Wright highlighted the six core programs operating under the center: Cystic Fibrosis, Hemophilia, Down Syndrome, Primary Care, Sickle Cell, and Cerebral Palsy. Dr. Wright also discussed target outcomes for the center that include best practices, exceptional patient experience, decreased hospital admissions, decreased patient and caregiver stress, effective preventive care, and disease specific management.

The Center for Special Health Care Needs is setup to assist patients of any age who have a childhood acquired chronic condition.

JFC Debriefing

Marie provided the GAC with an update on the February hearings. Legislatures expressed interest in potential population growth and the status of implementation of parts of targeted case management and the lifespan amendment. DDDS received written follow-up questions after the hearing and submitted responses for review.

Supported Decision Making

Terry provided GAC members with an information packet that was distributed in January with a follow-up workshop on February 4, 2018. Supported decision-making is a common topic among Community Navigators and families. Columbus is continuing to provide education on this topic, however many families are receiving opposite information from the school system urging parents to immediately become guardians as their children reach the age of 18. DDDS is working towards having a larger presence at school fairs and other events to educate families as well as school personnel. The Division is also providing guidance during transition IEP meetings. The goal is not to eliminate guardianship, but rather provide families with alternatives.

Waiver & LTSS Comparison

Marie led the discussion on the waiver and LTSS comparison handout for families. DDDS received various feedback from families at an EPIC meeting presentation. As a result, the Division will develop the comparison document in two different formats. The first will be a one-page comparison that lists the items. Families who are already familiar with the various services listed will use this document. The second document will provide a longer description of services to help families determine which would work best for them. After completion, both documents will be available on the DDDS website.

Down Syndrome/Alzheimer's Aging Population Supports

The GAC requested information from DDDS on how the Division is preparing for this group of people. DDDS has not yet addressed this issue in a formal or structured manner, but is adding it to their planning documents for future projects. DDDS and the GAC discussed the importance of this issue as individuals in this population are often diagnosed based on their disability instead of the health issue that is manifesting.

GAC members also discussed the issue of aging in place, and how DDDS can support these efforts. A suggestion was made to invite Steve Tull to speak to the GAC at a future meeting about the aging population and universal design.

Other Business/Announcements

Marie announced the selection of Marissa Catalon as the new Deputy Director for DDDS. Marissa's new role is effective Monday, March 19, 2018.

Members expressed concern over the amount of staff turnover within DDDS and providers agencies. A suggestion was made that providers work together with a temp agency to create a pool of workers that have already received training, are ready in the event of call outs, and can later be used as an applicant pool for vacancies. Currently, the buy out fees for employees coming from temp agencies are too high to make this a feasible option for providers. DDDS and the GAC agreed that while there are many barriers

in place, DDDS and provider agencies will need to find ways to overcome those barriers to address the issue of staff turnover.

Terry announced the Community of Practice meeting on June 18, 2018 with NASDDDS trainers.

Future Meetings

FY 2018 Governor's Advisory Council meetings will occur the third Thursday of the month at 11:00 a.m.

May 17, 2018	11:00 a.m. – 1:00 p.m.
June 21, 2018	11:00 a.m. – 1:00 p.m.